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Exploring perspectives of knowledge users about reporting on health equity in observational studies: a qualitative study informing the development of the STROBE-Equity reporting guideline

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Abstract

Background Health inequities arising from systemic factors and contextual conditions result in avoidable and unjust differences in health outcomes, with profound social and economic implications. Health inequities can frequently go unreported in observational studies. Observational studies can uniquely inform how we understand and address persisting health inequities through collecting, reporting and analyzing health equity factors using 'inclusive' methodological considerations. While the STROBE (STrengthening the Reporting of OBservational studies in Epidemiology) reporting guideline aims to improve observational study reporting quality, existing extensions lacked a specific focus on health equity. Engaging those who will use or be impacted by research ("knowledge users"), including participant-research collaborators, is central to bridging the gap between knowledge production and real-world application. Therefore, the purpose of this study was to gather a range of perspectives from these knowledge users as part of, and to inform, the development of the STROBE-Equity guideline extension, which aims to improve the reporting of equity-relevant considerations in observational studies.

Methods This study used a qualitative description approach, employing semi-structured key informant interviews and framework analysis to collect and analyze the views of researchers, policymakers, decision-makers, funders,

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journal editors, ethicists, and participant-research collaborators. Participants were purposefully sampled to reflect diverse perspectives from knowledge users with relevant experience on health equity reporting.

Results Eleven key informants participated in the interviews. Information from interviews was categorized into seven themes: "Clarifying equity", "Equity is dynamic", "The challenges of making equity claims", "Making reporting on equity feasible", "Using reporting guidelines to manage tension", "Potential for better outcomes", and "Nobody's perspective is neutral". Participants emphasized the need for standardized equity-relevant reporting practices and offered insight into challenges, opportunities, and strategies for integrating equity-relevant considerations into observational study reporting.

Conclusions Findings show that participants viewed equity as a complex concept and stressed the need for practical guidance to support equity reporting in observational studies. They highlighted barriers such as limited time, resources, and publication word limits, and perceived the STROBE-Equity extension as a valuable tool for structuring reporting, raising awareness, and encouraging reflection, with the potential to improve the quality and impact of equity-relevant research.

Keywords Health equity, Observational studies, STROBE-Equity, Reporting guidelines, Knowledge users, Qualitative research, Equity-relevant data, Framework analysis, Knowledge translation, Key informant interviews

Background

Definition, causes, and impact of health inequities

Health inequities are systematic and unfair differences in health status within and between various population groups [1, 2] arising fundamentally from the unequal allocation of power, money, and resources, which creates and sustains unequal distributions of the social determinants of health and leads to avoidable and unjust differences in health outcomes [3]. They are produced by political, cultural, social, and economic systems that shape the conditions in which people are born, grow, live, work, and age [3]. These inequities have significant social and economic implications for individuals and communities [2]. For example, limited access to healthcare can contribute to higher rates of preventable diseases, which affect individual health, increase healthcare costs, and reduce productivity in the community [4]. These effects are interconnected and contribute to the cycle of inequity, in which social and economic disadvantage erodes population health, and poor health in turn undermines education, employment, and capacity, trapping countries and communities in vicious cycles of under-development and conflict [3]. In contrast, advancing health equity can support more peaceful and cohesive societies, contributing to virtuous cycles that foster inclusive, equitable societies, and a healthier people and planet [3].

Importance of addressing equity-relevant data gaps in research for health

It is essential to address gaps in the collection, analysis, and consistent reporting of relevant equity factors to improve overall health equity [5]. Therefore, guidance on strengthening the reporting practices to drive the collection and reporting of equity-relevant data in research for health is needed [6, 7], particularly for informing evidence-based decision-making by policy and healthcare decision-makers [8].

Role of observational studies in research for health equity

Observational studies are prevalent in health-related research and make up a significant portion of public health as well as health systems and services research. They offer valuable insights to guide health and policy decisions [9, 10]. Observational studies often augment randomized controlled trials and provide critical insights into the epidemiology of health issues and the effectiveness of healthcare policies and programs on diverse groups [11, 12]. Due to the methodological limitations of observational studies, the researcher is not in control of the exposure or intervention [10, 12], and both internal and external validity of results rely on the collection of high-quality, unbiased data [6]. At the same time, observational studies are never neutral: decisions about which populations are included, how equity-relevant characteristics are defined and measured, and which comparisons are prioritized reflect underlying assumptions about whose health and inequities matter, and can either surface or obscure structural inequities rooted in unequal distributions of power, resources, and privilege [6]. Recognizing these embedded assumptions was a starting premise for our team and underpins the rationale for the STROBE-Equity extension, which is intended to prompt authors, reviewers, and readers to make such equity choices and implications more explicit and open to scrutiny [6].

These considerations are particularly pertinent in "equity-relevant" studies, which focus on groups of individuals who may face unfair and avoidable disadvantages or disparities reflected in various aspects of life, particularly in health outcomes, or which compare those groups to others [13]. This includes studies focused on

such populations and studies of general populations that stratify outcomes across PROGRESS-Plus characteristics (place of residence, race/ethnicity, occupation, gender/sex, religion, education, socioeconomic status, and social capital) [13, 14]. A definition of health equity relevant studies, specific to observational studies, can be found in Box 1 of the STROBE-Equity extension checklist and elaboration [14].

However, the collection and reporting of equity-relevant data in observational studies is suboptimal [15]. The gap in reporting of equity-relevant data in observational studies is multifactorial, reflecting upstream constraints on data collection (e.g., limited or poor-quality equity variables in data sources, small sample sizes for populations experiencing inequities), methodological and analytic uncertainties (e.g., uncertainty about how to operationalize and analyze equity-relevant factors) and downstream publication and incentive factors (e.g., journal word limits, lack of explicit expectations for equity-focused reporting, and discomfort naming inequities) [7]; these dynamics are evolving as equity-focused methods and expectations continue to develop [14].

STROBE reporting guideline and STROBE-Equity extension

The STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) reporting guideline aims to improve the transparency and completeness of the reporting of observational studies [16]. However, neither STROBE, nor its initial iterations provided specific guidance on how to report health equity considerations and equity-relevant data. To address this gap, our team conducted a multi-phase, two-stream project to develop the STROBE-Equity extension [6], which has now been published as an extension checklist and elaboration [14].

The STROBE-Equity project explicitly grapples with equity choices and implications by using a PROGRESS-Plus lens to examine who is included and how, by engaging diverse knowledge users (including people with lived experience and Indigenous partners) in defining what should be reported, and by treating the guideline itself as a social-justice-oriented tool to make the value-laden assumptions in observational research more transparent to readers and decision-makers [6]. Consensus-based guidance can primarily address these domains by clarifying what should be reported; providing examples of good practice; encouraging reflexive consideration of equity in design, analysis, and interpretation; and signalling to authors, reviewers, and journals that equity-relevant information is expected and valued, even as equity-related methods and norms continue to change and structural barriers to data generation require policy and system-level solutions [6, 14].

This qualitative key informant interview study formed one component of the multi-phase STROBE-Equity project and was undertaken to inform the development of the STROBE-Equity guideline by identifying themes and principles that guided reflection, consideration, and confirmation of the final checklist items and informed the consensus process.

Improving knowledge translation through knowledge user engagement

High-quality research can lead to improved and sustainable health outcomes, which in turn can promote healthier communities [17, 18]. Nonetheless, a lack of contextually-relevant knowledge translation practices often impedes fully realizing these research advantages [19, 20]. One solution is intentionally engaging "knowledge users" who will use or be impacted by research throughout the research process [21]. The categories and characteristics of knowledge users are described in detail elsewhere [6]. 'Engagement' in the research process refers to an arrangement in the governance of the research process whereby those who influence, administer, and/or use healthcare systems partner with one another as equals on a team to co-produce knowledge [21].

A collaborative approach with knowledge users in health research may bridge the "know-do" gap between knowledge production and its real-world application, leading to more relevant and impactful studies [22, 23]. This is particularly important in equity-relevant research as knowledge users will contribute expertise that reflects their context, needs, and aims [23, 24]. For this study, we used key informant interviews with knowledge users who hold expertise or experience in conducting equity-relevant research [25].

Study aims and objectives

The primary aim of this study was to gather a diverse and comprehensive range of perspectives from knowledge users whose experience spans the research lifecycle, including patients and members of the public with lived experience who are participants and research collaborators, to inform and enrich the broader research agenda for developing a STROBE-Equity reporting guideline extension. Our objectives were to capture their perspectives on (1) how health equity is currently reported on in observational studies, (2) participants' needs regarding the reporting of equity-relevant information in observational studies, and (3) potential challenges that may limit the reporting of equity-relevant information [6].

Methods

As per the protocol of the overarching STROBE-Equity reporting guideline project [6], the qualitative study phases used two streams of interviews to collect data to inform the development of that guideline: one with Indigenous knowledge users, which is currently in progress,

and one with global knowledge users, which is reported on in this paper. The overarching project is grounded in a pragmatic worldview using an integrated knowledge translation and social-justice-oriented approach that prioritizes generating practical, usable guidance to address structural inequities in health by improving how equity is reported in observational studies, and this paradigm was collectively agreed upon by the diverse research team as common ground for working across disciplines, roles, and lived experience [6]. In practice, team members brought different disciplinary and epistemological commitments to the collaboration but agreed for purposes of this project to adopt this shared stance and set of underlying concepts as the basis for our research approach.

The Bruyère Health Research Institute's Research Ethics Board approved this study in October 2021 (Protocol # M16-21-025), which was funded by the Canadian Institutes of Health Research (438315).

Positionality

The STROBE-Equity team represents people from diverse countries, genders, ethnicities, languages, career stages, and disciplines. Our expertise spans qualitative, quantitative, and mixed-method approaches, as well as collaborative research and health policy. Our core values are equity, diversity, and inclusion, focusing on inclusive health research that honours and includes the lived experiences of those who have firsthand knowledge of inequities, addresses the genuine challenges and needs faced by diverse populations, and improves health outcomes for everyone.

Design

In this study, a qualitative description approach [26] was chosen to align with the pragmatic worldview of the broader research project [6]. This approach is well-suited for research that seeks to directly understand and describe the perspectives of those experiencing a process or phenomena, particularly through the use of purposeful sampling to select participants with relevant experience and knowledge [27]. To achieve this, we conducted a qualitative study using semi-structured key informant interviews and framework analysis [28]. Framework analysis (or the framework method) is a structured approach to qualitative data analysis, ideally suited for applied research [28, 29]. These methods have proven effective in guideline development by identifying essential practical context and considerations, providing in-depth perspectives on concepts not well-described in literature, and surfacing views that might not be captured through surveys or meetings alone [30]. We adapted our approach from the key informant interview method used to develop the Consolidated Standards of Reporting Trials (CONSORT)-Equity guideline [30], specifically modifying the interview guide to focus on observational studies rather than randomized controlled trials (see Table 1 for the interview questions). The framework analysis approach is highly compatible with the qualitative description approach; both prioritize remaining close to participants' original accounts and generating practical, actionable insights that are grounded in the data rather than abstract theory [26–28]. It was selected for its systematic and transparent process for managing and analyzing qualitative data, ability to facilitate analysis of diverse respondent data from multi-disciplinary perspectives, and appropriateness for both case- and theme-based analysis [28]. This approach is not tied to any specific theoretical orientation, offering flexibility and aligning with the pragmatic worldview that underpins our overall study [28, 31].

Interviews were conducted between December 2022 and December 2024 to inform the ongoing phases of the STROBE-Equity guideline development. The first round of interviews (n = 8) and subsequent themes were used to inform the STROBE-Equity extension checklist and elaboration [14]. In response to feedback from the project advisory group about the need to broaden the range of perspectives, we conducted three additional interviews with stakeholders whose views were not yet well represented. For the present qualitative study, we report on this expanded set of 11 key informant interviews; the additional three interviews were completed before the consensus activities and are included here to provide a more complete account of stakeholders' reflections that informed the development of STROBE-Equity.

Sampling and participants

In our study protocol, we determined that the sample size would be based on theoretical saturation [6], which occurs when additional interviews no longer provide new insights relevant to the research question [32] and meaning that the themes have been thoroughly explored [33]. We used a purposeful sampling approach [34] to invite individuals with experience in conducting, using, or overseeing equity-relevant observational research. Eligible participants included researchers, policymakers, decision-makers, funders, journal editors, ethicists, and participant-research collaborators involved in the broader STROBE-Equity project or with recognized expertise in health-equity-focused research and reporting. Invitations were sent via email through the STROBE-Equity networks, with no obligation to participate, as outlined in our protocol [6]. Participants were drawn from multiple world regions, with representation from the Global North and Global South. To protect confidentiality in a small, specialized community, we do not report country-level details, however, we ensured variation across role (e.g., researcher, policymaker, editor, funder, ethicist,

Table 1 Interview questions

Topic	Question	Probes
Experience	Q1. Do you have any experience with reading/using/doing/participating in observational studies you might consider equity-relevant?	Some experience? None? Interest in? Value of? Can you explain your role? When was this?
Familiarity with checklist use	Q2. Would you explain your experience with STROBE?	Some experience? None? Interest in? Value of? Can you explain your role? When was this?
Feedback on the checklist. [Make sure that the participant has a copy of the checklist in front of them]	Q3. Now I will review each section of the STROBE checklist with you and will ask you about it, okay? For the section titled [title/abstract et cetera – each section of the checklist], is it important that the information on how equity is relevant for the trial is reported for the [title/abstract et cetera]? [This process will be repeated with each section of STROBE checklist – there are six sections: title/abstract, introduction, methods, results, discussion, other information. There are subsections for each section, and it is expected that participants will refer to subsections and issues of particular importance, if needed].	Why? Are there any reasons that it might be challenging to include information on how equity is relevant for an observational study in this section? [For each section of the STROBE checklist]
Perceived use of the checklist	Q4. Would you use the STROBE checklist if it was modified to include equity-relevant considerations?	Why or why not?
Perceived relevance of the checklist	Q5. Would you encourage others to use the STROBE checklist if it was modified to include equity-relevant considerations?	Why or why not?
Additional comments	Q6. Any other comments or suggestions to make the checklist better for reporting equity-relevant observational studies?	

Questions and table adapted from Jull J, Petticrew M, Kristjansson E, Yoganathan M, Petkovic J, Tugwell P, et al. Engaging knowledge users in development of the CONSORT-Equity 2017 reporting guideline: a qualitative study using in-depth interviews. Res Involv Engagem. 2018 Dec;4 [1]:34

participant-research collaborator) and regional context in line with the sampling approach used in the STROBE-Equity consensus work [6, 14]. A map of the place of residence and country of origin of STROBE-Equity team members that were solicited for participation can be found in the STROBE-Equity extension checklist and elaboration [14].

We found it particularly important to engage members of the STROBE-Equity group who have been, or currently are, participant-research collaborators, as knowledge users [6], to foster an inclusive process that gives insight into the context and realities of the implementation of research that may not arise otherwise [21]. To operationalize this, our recruitment emails explicitly targeted STROBE-Equity team members with lived experience or participant-research collaborator roles, and we monitored responses to ensure that at least some invitees from these groups were represented in the final sample.

Procedure

All interviews were conducted by research assistants (DS, KA), with most being conducted by one research assistant (DS), who has extensive formal training and experience conducting interviews, under the guidance of one of the Principal Investigators (JJ), a researcher who has led prior studies that involved key informant interviews and engagement activities with a range of knowledge user participants [30]. The semi-structured interview guide was adapted by core group members (VW, SF, LB, JJ, EG) and pilot-tested (JJ, OD, KA). The research assistants participated in trial interviews with key team members (JJ, OD) to ensure consistency in the key informant interview guide question and prompt approach.

Written informed consent was obtained from all individuals who agreed to participate in the study. Interviews were carried out via video conferencing and research assistants digitally recorded audio (DS, KA). At the beginning of each interview, participants were briefed on the broader context of the STROBE-Equity reporting guideline extension development, including the rationale for its development, how their interviews would contribute, and what they could expect during the session. If clarification of the concept of health equity was needed, a definition [1, 2] was provided. Participants were asked to share their experiences related to equity-relevant observational studies and the STROBE reporting guidelines. The interviewer then shared the original 22-item STROBE reporting guideline and asked the participant to reflect and expand on the importance and challenges of reporting on equity-relevant considerations in each section (Title and Abstract, Background, Methods, Results, Discussion, Other Information). Follow-up questions were asked throughout the interviews to capture the context, experiences, and reasoning behind their responses. The interviews concluded with questions about the perceived use and relevance of a STROBE-Equity extension and solicitation of additional comments or suggestions. Following the interviews, participants were asked to complete a demographic questionnaire. We report professional roles as participants described them and do not add additional details where this could risk confidentiality.

The digitally recorded interviews were manually transcribed verbatim by an independent professional transcriptionist, anonymized, and then reviewed by two research team members (DS, JJ). The transcribed interviews were offered to all participants for accuracy verification, none of whom wished to review their transcript.

Data analysis

The analysis was conducted by two independent researchers (DS, JJ), with DS leading the process and JJ providing secondary confirmation. A third researcher was available to resolve disagreements (VW).

Our analytical process adheres to the seven stages of framework analysis: (1) interview transcription; (2) content familiarization; (3) initial coding; (4) developing a working analytical framework; (5) applying the framework; (6) charting data into the framework matrix; and, (7) interpreting the data to identify key themes and relationships [28]. Initial coding was primarily inductive: both coders (DS, JJ) read each transcript line-by-line and generated data-driven codes to capture participants' meanings (e.g., "social, political, and historical tension," "reporting as a tool for guidance, awareness, and permission"). We used Microsoft Excel to manage the data, with each transcript represented as a case (row) and codes as columns, allowing us to sort, filter, and compare coded segments within and across interviews in line with the matrix-based approach described in the Framework Method [28]. As coding progressed, we began to group related inductive codes into high-order categories (e.g., "Equity is dynamic," "The challenges of making equity claims," "Making reporting on equity feasible," "Using reporting guidelines to manage tension"), which together formed our working analytical framework. This framework then guided a more deductive cycle of coding, in which we systematically applied the agreed codebook across all transcripts within and between cases.

In our study, to ensure its robustness, we sought and incorporated iterative feedback from the study executive committee (n = 10), comprising the co-principal investigators, trainees, and researchers responsible for leading the empirical studies (described in more detail in the STROBE-Equity extension checklist and elaboration [14] and the STROBE-Equity website [35]). We (DS, JJ) engaged the committee and the wider team at key stages to ensure a collaborative process throughout the analysis. Initially, we briefed team members (VW, SF, LM, XW, OD) on the methodology and preliminary findings, soliciting their input. After developing the initial framework, we presented it to the Principal Investigator team (VW, SF, LM) for feedback before proceeding with further coding. A core research team, consisting of the study PIs and a student engaged in the study (JJ, VW, SF, LB, EG, DS), consulted and sought feedback from the wider STROBE-Equity team. Member checking took place during four cycles of manuscript review, where the STROBE-Equity project team, including all participants, were invited to review the manuscript to check for accuracy, validate interpretations of findings, and offer feedback. This iterative approach fostered ongoing reflexivity and culminated in a final review and validation of the completed analysis by the wider team, ensuring consensus on the results.

To ensure transparency and completeness, we used the Guidance for Reporting Involvement of Patients and the Public (GRIPP) 2 Short Form Reporting checklist to report on public engagement in our study [36] (Supplementary file 1) and the Standards for Reporting Qualitative Research (SRQR) reporting guideline to report on our self-study [37] (Supplementary file 2).

Results

Participant characteristics

Eleven key informants agreed to participate in the interviews. After eight interviews, conceptual consistency was found. To ensure theoretical saturation, and to capture a broad range of perspectives, an additional three interviews were conducted.

Reported participant roles within the research ecosystem included participant/patient/research collaborator, ethicist, researcher, journal editor, funder, and policy/decision-maker. Many of the participants reported representing multiple roles. Participants reported varied intersections of engagement in equity-relevant observational studies (reading, using, doing, or participating in) and range in professional experience (from one year up), with most reporting more than ten years. Participants reported varied methodological backgrounds, with over half indicating experience across all study designs (quantitative, qualitative, mixed-methods, systematic reviews). Over half of the participants report that their region of work is international, not just the country in which they reside, and meaning that they bring a global perspective to their work. All participants indicated having experience with STROBE reporting guidelines (using, reporting, or referring to). A summary of participant characteristics captured in the demographic questionnaire can be found in Table 2.

Participant-derived themes: descriptive insights on a STROBE-Equity extension

Consistent with the qualitative description approach, our analysis presents findings in straightforward, accessible language that closely reflects participants' own words and perspectives [26, 27]. Seven themes relate participants' perspectives on potential individual and contextual challenges, possible solutions for reporting on equity, and the relevance and application of a STROBE-Equity

reporting guideline extension: "Clarifying equity", "Equity is dynamic", "The challenges of making equity claims", "Making reporting on equity feasible", "Using reporting guidelines to manage tension", "Potential for better outcomes", and "Nobody's perspective is neutral".

Clarifying equity

The need for clear and consistent definitions of equity and equity-related terms was identified as a significant theme among most participants. Participants emphasized that different researchers may have varying interpretations, highlighting the critical importance of establishing a common language in equity-relevant research and policymaking. Participants suggested that clarification across disciplines and methodologies may ensure that future readers and researchers can accurately reference and apply the concepts within the same scope. They report that the challenge extends to policy evaluation, where consistent reporting methods are essential for effective comparisons of policy benefits and drawbacks. Most participants indicated that uniformity in reporting would facilitate more meaningful analyses and comparisons across different studies and policies, ultimately leading to more informed decision-making in equity-related initiatives:

> *I think it's important to report or to define the equity-related terms - the ones you used in your article. Because different researchers have different definitions…It would be good to define all the terms you used to make sure people in the future who use your readout are referring to the right one, or they're referring to the same scope of this group that they can directly use. (Interview #2: researcher)*
> *What I think the challenge may be is having information reported in the same way…So you can actually say, Look, this policy maybe has these benefits, but this policy also has this, and you can compare them more easily. (Interview #9: ethicist/researcher)*

To address the ambiguity surrounding equity-relevant terminology and scope, one participant recommended providing researchers with guidance that clarifies when, and to what extent, they should consider equity in observational studies:

> *[It might be useful to] lead with some type of preamble that talks about the inclusion of equity in observational studies, or the degree of inclusion. Something to help the authors determine whether or not they want to use the equity extension, or whether they want to continue…or just use the original. So, I guess there needs to be some kind of clear discussion of the role of equity. (Interview #3: researcher/journal editor)*

Equity is dynamic

Most participants described the complex and multidimensional nature of equity as a concept, emphasizing its pervasive influence throughout the research lifecycle. They recognized that equity is not simple and static, but rather a dynamic and intricate construct that can manifest in numerous ways and arise from a wide array of factors and characteristics. This complexity is further amplified by the observation that equity-relevant issues can apply to almost any research topic, particularly in

Table 2 Participant characteristics

Characteristics	Frequency
*Role in health research	
Funder	1
Ethicist	1
Researcher (includes clinician-researchers)	7
Participant/research collaborator	3
Publisher/journal editor	3
Policy/decision maker	1
Other (please specify)	4 (professor, author, patient collaborator, pharmaceuticals)
Would you describe (any of) your role(s) as equity-relevant? Relevant meaning in that role you are concerned with equity in some way (advancing it, making it apparent).	6 (yes)
*Experience with equity-relevant observational studies	
Reading	10
Using	8
Doing	5
Participating in	4
Years of experience	
1–5	3
5–10	1
More than 10	6
Unknown	1
*Type of research experience	
Quantitative	1
Qualitative	0
Mixed methods	2
Systematic reviews	4
All	7
*Experience with STROBE reporting guidelines	
Used	5
Reported with	3
Referred to	7
Region of work	
Country of residence	6
International	5

*Participants could identify as belonging to more than one category

Note: Roles are reported as provided by participants and not further specified where this could affect confidentiality

the health field. Some participants suggested that equity should be a fundamental component of all large-scale observational studies and that researchers should consistently incorporate equity considerations into their work, regardless of the specific focus of their study:

> *There are so many things that could result in inequities or characteristics that result in equities. (Interview #5: researcher)*
> *…almost every topic, there might be something related to health equity. (Interview #2: researcher)*

Several participants articulated how integrating equity considerations throughout the study lifecycle can incite more profound thinking about health issues, raise essential questions, and reveal underlying inequities in results. One participant noted that if equity is consistently considered, researchers are more likely to uncover disparities that might otherwise go unnoticed. Another participant pointed out that discussions surrounding findings should explore the reasons behind observed results, prompting critical questions about whether those findings contribute to deepening existing inequities and a more nuanced analysis of their data from a health-equity lens. Some participants suggested that by fostering this level of inquiry, researchers and policymakers can better understand the complexities of health disparities that may contribute to more equitable outcomes in future work:

> *For me, it is at the heart of it in the discussion session; picking up on whatever findings that you might have come across in your results. Why is that happening? Is it still deepening inequalities or inequities? (Interview #8: researcher/policy and decision-maker/journal editor)*
> *I think that's a part [including information about how equity is relevant to the study in the results section] where you can go deep to figure out maybe there are some other factors, health equity factors, you haven't considered. And to make these more useful for the readers. (Interview #2: researcher)*

The challenge of making equity claims

Most participants emphasized the influence of contextual and systemic factors on the reporting process. They contemplated how those factors could create tension and potentially impact researchers' decisions to engage in reporting on equity, and how they do so. A key insight shared by some participants was the non-neutral nature of equity as a concept, particularly in the current social and political climate, adding another layer of complexity to the implementation and use of an equity-extension reporting guideline. Some participants noted that the very concept of equity itself might incite potential resistance to equity-relevant research. They suggested a need for researchers to balance the imperative of reporting equity-relevant considerations with sensitivity to the broader societal context, highlighting that this may require careful navigation of political landscapes when reporting on equity-relevant issues to ensure their research can be effectively conducted and disseminated:

> *People that challenge just the issue of equity itself will be an issue. (Interview #1: participant/research collaborator)*
> *I mean I guess nowadays I can see that terms like EDI [Equity, Diversity, Inclusion] or intersectionality are stigmatized in certain areas and are being even more than stigmatized - censored. So, I can see why that could be complicated. (Interview #11: researcher/participant/research collaborator)*
> *It would be important to report on those things [equity-relevant considerations] …but also to be mindful of first any statements that are divisive, especially in the title. (Interview #6: funder/policy and decision-maker)*

Making reporting on equity feasible

Most participants highlighted practical obstacles that may pose challenges for researchers who are incorporating equity-relevant considerations, referring specifically to time limitations, resource constraints, and publication word-limit restrictions. They noted that the additional layer of equity-relevant factors requires more time for data collection, analysis, and interpretation, and can substantially increase the complexity of studies, which can be challenging. Further, journal word-count limits may be problematic, potentially forcing difficult decisions about what information to include or exclude. One participant suggested that the burden on researchers must be balanced with the importance of reporting on equity, noting the adaptations to the research system may need to facilitate equity-relevant considerations in observational studies:

> *Bringing equity adds a whole other layer into the paper. And this can make these publications quite long. And this could cause trouble as well. (Interview #3: researcher/journal editor)*
> *I think also, especially when it comes to, let's say sample size calculations or power calculations, when you try to factor for so many things, it makes the trial bigger or the observational study bigger and more complicated. (Interview #5: researcher)*
> *Journals have a really important role. I think a stick approach, as opposed to a carrot approach, can be*

beneficial here. So, by that, I mean like the journals requiring it. I think journals requiring reporting to be done in a certain way is probably how you're going to get it done consistently in a certain way... And so I think there's a role for journals to require it. (Interview #9: ethicist/researcher)

Some participants noted that reaching certain populations is not always feasible, which can hinder equity-relevant data collection. They suggested that a commitment to openly acknowledging these limitations is essential, and recommended that even when equity-relevant goals are not met, documenting these shortcomings transparently can promote accountability and improvements in research practices:

I think pretty much [the challenges in reporting] relate to how you conduct the research. Like whether you can reach these people. I think that's the hardest, the most difficult part for research…So you just report this transparently. (Interview #2: researcher)
I don't know if it adds very much work because if they didn't consider it, they didn't consider it. That's how it is. It's a sentence. (Interview #8: researcher/policy and decision-maker/journal editor)
Even if you set the [equity-relevant research] goals and didn't meet them, I think it's important to be talking about all those kinds of things. (Interview #11: researcher/participant/research collaborator)

Using reporting guidelines to manage tension

Most participants noted the potential of the STROBE-Equity extension as a tool to raise awareness, provide structure, and offer guidance for incorporating equity-relevant considerations in their research. Several participants shared how an equity extension may broaden perspectives and encourage reflection on biases, ultimately catalyzing discussions toward equity. Some noted that it may also influence the research process itself, prompting researchers to consider who may be overlooked by their work, as well as who might be receiving disproportionate benefits, and potentially leading to more equitable study designs:

[The guideline can be used] to steer or to bring discussion to equity. Because not everyone thinks of it that broadly. (Interview #4: patient collaborator)
I feel that we don't give due attention to inequities in policy or research necessarily. And having a reporting guideline makes people think about that. And [while] I think this is about all reporting guidelines, there's a secondary benefit or secondary impact, which is about thinking about the research itself. (Interview #9: ethicist/researcher)
I think explicitly calling out equity is important. Because it forces people to think about [whether] there are people that we're not helping with what we're doing, or who are being helped less? Or consequently, you know, are there people that are getting greater advantages from these things? …I think demonstrating forethought of those unintended consequences or actively looking for differences is really important. And that comes through in your methodology, or should come through in your methods, right, is how you anticipated and addressed potential inequities in your research design. (Interview #9: ethicist/researcher)

A few participants noted that researchers, institutions, and funding bodies seek practical guidance on standardizing equity-relevant reporting globally. Two participants stated that the guidelines may be a valuable tool for funding bodies and journals to hold researchers accountable for integrating equity-relevant considerations in their work:

Everybody's looking for a way to provide the how, how to do it [standardize reporting on equity at a Global level]. (Interview #6: funder/policy and decision-maker)
The guidelines are relevant also to funding bodies so that they can also make sure that researchers are being responsible and paying attention to equity issues in observational studies. (Interview #8: researcher/policy and decision-maker/journal editor)

One participant viewed the role of equity-relevant reporting guidelines as empowering researchers by providing a framework that supports ethical practices:

…one of the things we talked about was how regulation can be autonomy enhancing…So the regulation has a role there that allows people to do the right thing…which they wouldn't be able to do if that regulation wasn't there. (Interview #9: ethicist/researcher)

Potential for better outcomes

Some participants emphasized that normalizing the practice of reporting on equity-relevant considerations in observational studies may have positive downstream implications in informing real-world decisions:

There are all sorts of potential benefits for looking at large administrative databases and big data, and

you're using those to also inform decisions alongside randomized trials. So that's a realization that in real life circumstances, people are going to wish to use [observational studies] for very good reasons. (Interview #7: journal editor)

A few participants noted that a lack of reporting of equity-relevant data impacts evidence syntheses processes and outcomes. They suggested that more consistent and comprehensive reporting of equity-relevant considerations in observational studies would enhance the synthesis of evidence, making reviews more efficient and potentially more robust:

Certainly, for when I'm doing my scoping reviews, especially scoping reviews on observational studies that are focused on equity, we're having to go and try to look at all of the studies and find equity considerations. Should the studies have already reported equity considerations, it would make our scoping review or our reviews much easier. (Interview #3: researcher/journal editor)

One participant stated that more detailed reporting may be particularly valuable to decision-makers, providing a stronger foundation for informed decision-making and policy development that considers the diverse needs of various population groups:

It's very useful for the evidence users to get the information to support their research, or to support the policymakers, or to support other decision makers to make a more appropriate plan for different populations. (Interview #2: researcher)

Nobody's perspective is neutral

A few participants challenged the notion of a neutral scientific lens, stressing that research decision-making and reporting on equity begins with – and requires – the self-awareness and reflexivity of the researcher. They stated that researchers are shaped by their sociocultural backgrounds and experiences, influencing how they write and interpret their findings. One participant highlighted that the dominant perspective might be mistakenly perceived as neutral or culturally unbiased. Another participant suggested the need for more visible conversations about these inherent biases and the choices made during the research and publication process. Some participants recommend self-reflection and transparency as crucial steps in addressing equity-relevant considerations throughout the research lifecycle:

The major challenge is we are living in a white society, socialized to think that it doesn't have a culture, or that its perspective is neutral, when nobody's perspective is neutral. (Interview #10: researcher)

We all are socialized into society. And those thoughts are coming with us to our paper when we write it. (Interview #10: researcher)

We're always making choices. And multiple things inform those choices about what ends up being the papers that end up getting published. But I guess I just wonder - and I'm not saying that this would be for this guideline - but it does make me wonder like is there any way that we should be having those conversations in a way that is visible? (Interview #11: researcher/participant/research collaborator)

Main findings

Seven new themes that had not been identified in previous research activities related to the ongoing development of STROBE-Equity reporting guideline extension yielded novel insights on integrating equity-relevant considerations in observational study reporting. All participants responded to the interview questions with thoughtful discussions about equity and the future implications of the STROBE-Equity extension. The key informant interviews generated discussion about the potential importance and impact of the proposed items for reporting equity-relevant data and allowed for the voices of knowledge users to shape and validate the development of the reporting guidelines, potentially enhancing the applicability and use of the equity extension in real-world settings. A comprehensive overview of the contributions from this study's findings in the development of the STROBE-Equity reporting guideline extension, organized by theme, is presented in Table 3.

Discussion

Interest-holder engagement has been used in the development of multiple equity-relevant focused reporting extensions including CONSORT-Equity (randomized controlled trials) [30], SAR4Research (social accountability processes, context, study designs, and outcomes) [38], and PRISMA-Equity (systematic reviews) [39, 40]. Our study parallels the approach used in developing the CONSORT-Equity extension, with an aim to capture valuable insights from a range of knowledge users, including participant-research collaborators, as key informants [30].

All the equity-relevant reporting guideline extension studies engaged diverse stakeholders, made efforts to include geographic diversity (though with varying emphasis), and sought representation from various groups including researchers, journal editors, and methodologists. All explicitly recognized the importance of including perspectives from those who would apply the

Table 3 Contributions to the development of the STROBE-Equity reporting guideline extension

Category 1: "Clarifying equity"	This category contributed to thinking about terms related to the operationalization of health equity and description of the equity extension items that authors and readers of the guidance would need to know to understand the guideline. We have included in the reporting guideline a box of terms defining health equity, populations experiencing inequities and describe tools to operationalize these definitions in studies (Box 1: Definitions).
Category 2: "Equity is dynamic"	This category promoted us to review the reporting guideline extension items to ensure that they would encourage the reporting of contextual information (e.g., social, economic factors) that could affect health equity as well as highlight this in relevant elaboration sections. For example, STROBE item 6, Participants, extension item Eq. 6, recommends authors describe whether characteristics associated with inequities were considered in the selection process (e.g., eligibility criteria, matching). Recognizing that contextual issues are important and relevant to eligibility criteria, we have included in the elaboration of the Eq. 6 item the importance of considering those accordingly.
Category 3: "The challenges of making equity claims"	This category affirmed the importance of the reporting guideline extension in encouraging the explicit reporting of authors' motivations for addressing health inequities. Making claims about health equity requires careful consideration of the study's context and the underlying rationale for addressing equity in a specific setting. Thus, clearly articulating these factors is crucial for contextualizing the research and ensuring that health equity claims are well-grounded and relevant to the study's objectives and motivations. This helps enables readers to situate any findings or claims about health equity in the context of the study and enables interpretation of its contribution.
Category 4: "Making reporting on equity feasible"	This category emphasized the importance of a feasible and useful reporting guideline, which influence how we developed the final extension items. In our writing working group, we focused on ensuring the final guideline was as short and parsimonious as possible. This sometimes involved combining more than one item or deciding that some items were not needed. We based these decisions on the overall goal to create a feasible guideline. For several items, we decided that the main STROBE guideline and checklist was sufficiently broad to be inclusive of equity-focused issues. For example, we initially had two equity extension items for the STROBE item on selection bias. However, we decided these were extraneous since any efforts to reduce selection bias related to health equity would be reported by adhering to the main STROBE reporting guidance.
Category 5: "Using reporting guidelines to manage tension"	In the context of reporting on health equity, tension arises from the complex interplay between social and historical factors that influence health outcomes and the challenges in accurately representing these within broader frameworks, including the composition of the research team. STROBE item 4, Study design, equity extension item Eq. 4, recommends that authors describe the research team composition, particularly if it includes individuals with lived experience of inequities. This is a novel addition to reporting standards for quantitative studies and the key informant findings of managing tensions strongly supports our rationale for including this item. The composition of a research team can have a profound impact on how health equity issues are identified, addressed, and reported. Including individuals with lived experience of inequities brings a deeper, more authentic understanding of equity issues, which can ultimately improve the relevance and inclusivity of the findings. Moreover, individuals who experience inequities have been, in many cases, exploited through unethical research practices. Their inclusion in the research process helps rectify this historical injustice by validating their lived experiences and incorporating their insights into research that affects them. This enriches the quality and ethical integrity of the research and supports grounding the research in the realities of the communities most affected by inequities.
Category 6: "Potential for better outcomes"	In the context of reporting on health equity, the potential for better outcomes includes ensuring adequate representation of participants from groups experiencing inequities, increasing the likelihood that the findings will be relevant and applicable to those populations. This category contributed to thinking about keeping items in the equity extension that would have broad implications on the health outcomes of populations experiencing inequities. STROBE item 10, Study size, equity extension item Eq. 10, related to interpreting the results while considering the representation of the study sample and the implications of the findings on health equity. This is particularly important for addressing health disparities, as underrepresentation of people experiencing inequities can skew the findings and limit the applicability of interventions to those who face the greatest health inequities.
Category 7: "Nobody's perspective is neutral"	This category expands our understanding of the social context in which equity-relevant reporting may be engaged with by researchers and interpreted by end-users and is not directly related to the development of the reporting guideline.

guidelines in practice and acknowledged practical barriers to comprehensive reporting, such as journal word limits [30, 38, 40].

While these three studies share important commonalities in their approach to developing reporting guidelines for equity-focused research [30, 38, 40], our study contributes several distinctive insights that advance the field in novel ways. First, knowledge users in this study conceptualize "equity" as dynamic, rather than static. While other studies focusing on reporting *about* equity, this study deepens on the fundamental *nature* of equity itself and how this understanding impacts reporting. Building on recent work that defines equity simultaneously as a conceptual construct, a benchmark, and as experiential, our findings support the view of equity as a dynamic value judgement regarding the level of fairness and justice in social systems, structures, and practices [41]. Attending to equity in this way highlights that reporting decisions are never neutral, and are shaped by underlying worldviews about justice, accountability, and whose experiences are made visible.

Second, participants explicitly challenge the notion of scientific neutrality in research for health equity and focus on reflexivity as a potential avenue to promote transparency in understanding – and reporting on – how researchers' sociocultural background influence how

they interpret and report findings. This insight suggests that research team composition and positionality may constitute important sources of bias that authors should make transparent in observational studies. Equity-related decisions in research are also shaped by the composition and positionality of research teams themselves. Differences in disciplinary training, geographic location, and sociodemographic experiences can influence how equity problems are framed, which questions are prioritized, and what forms of knowledge are considered legitimate, underscoring the importance of reflexivity not only in analytic choices but also in how research teams are constituted. During the development of the STROBE-Equity extension, we discussed reporting team composition and positionality in aggregate as a practical way to make power dynamics and expertise visible while reducing risks of identifiability and stigma [14]. Encouraging positionality statements in all research, analogous to current practice in qualitative research [42], is currently a topic of discussion across the wider research community [43]. These ongoing discussions about the role of positionality and how to use the *process* of developing positionality statements, may help researchers move away from an implicit "neutral scientific lens" and introduce reflexivity into how team composition and potential bias are reflected on and reported.

Third, the recognition of the socio-political dimensions of equity-relevant reporting is absent from the three other studies and raises important questions about the context in which researchers conduct their work and navigate their decision-making. A prior critical interpretive synthesis has highlighted how broader political-economic priorities can constrain health equity efforts, signalling that reporting choices are made within environments that may not value, or may actively resist, progress for health equity [44]. Our participants' reflections on tension, resistance, and pushback around equity-focused language echo these concerns and suggest that socio-political context is itself a key influence on if, and how, equity-relevant reporting occurs.

Beyond challenging scientific neutrality and emphasizing reflexivity, participants in our study also pointed to the pervasive, often unspoken equity implications of seemingly technical choices in observational research, such as which questions are asked (or avoided) and how they are formulated, which populations are included or excluded, how equity-relevant variables are defined and measured, and which comparisons and outcomes are prioritized. Equity-relevant decisions also arise across the broader research lifecycle, including the composition and disciplinary diversity of research and writing teams, analytical and data-processing choices (including the use of emerging tools such as artificial intelligence), funding and sponsorship contexts, and the intended audiences and uses of research. Recognizing these influences reinforces the importance of viewing equity-oriented reporting guidance within a wider ecosystem of research governance and practice. These findings align with prior work showing that health inequities are produced and sustained through unfair distribution of resources, wealth, and power, and that equity work requires explicit attention to how routine scientific and governance practices can either interrupt or reproduce these distributions [44]. If equity-oriented knowledge-to-action efforts do not deliberately identify and mitigate power imbalances (including how "legitimate" knowledge is constructed), there is real risk in doing little to advance equity – or even masking inequities [41].

Participants also emphasized that ethical practice in equity-relevant observational research extends to how researchers and journals respond to practical constraints such as time, resources, and word limits. In their view, acknowledging when equity-relevant goals could not be met, and transparently describing sampling limitations, missing equity variables, or analytic compromises, is itself an equity practice. This transparency may make visible how systems of power, resourcing, and feasibility shape what can be known or reported, rather than allowing absences to be interpreted as neutral or unproblematic. Thus, participants framed ethical reporting as inseparable from equity-oriented reporting: ethical transparency about constraints and shortfalls is a concrete way to avoid superficial "equity" labels and to support accountability for how research practices may reproduce or disrupt unfair distributions of power, resources, and voice.

This study began by examining perspectives on the STROBE-Equity extension but evolved into a broader discussion about equity in research and its intersection with systemic, contextual, and socio-political factors. Participants highlighted that equity choices are present at every stage of research – from priority-setting and partnership formation, through data collection and analysis, to reporting and dissemination – and that STROBE-Equity can potentially be used as a technical checklist *and* a tool to critically examine, and where possible, shift how power and resources are distributed in research processes and infrastructures. Our findings suggest that STROBE-Equity can be used not only to improve completeness of reporting, but also to encourage readers, reviewers, and decision-makers to ask who benefits from choices about how equity is described, what data are collected, and how results are analyzed. This aligns with wider calls to better link evidence to action for health equity and to shift power imbalances in global health research [45]. While the STROBE-Equity extension provided a framework for discussion, participants emphasized the need to address

larger questions about the consideration of equity in research and policymaking.

A recent *Lancet* article describes how science transcends borders, thriving as a global collaborative effort where discoveries, innovations, and challenges in one country inevitably ripple across the world, underscoring our shared responsibility and interconnected future [46]. The article goes beyond stating *what* is happening with providing explicit guidance about *how* to take action to overcome barriers to pursuing equity-related scientific progress [46]. Our study addresses the pressing need for actionable guidance by capturing the perspectives of knowledge users on how to improve equity-relevant reporting in observational studies; these insights directly informed the development of the STROBE-Equity extension, which offers practical guidance to operationalize the Lancet article's call for explicit direction on advancing equity in research.

Strengths and limitations

This study involved a range of participants with varied roles from the research ecosystem. Key strengths of the study include diverse international participation, cross-disciplinary collaboration, and an iterative, systematic approach to data collection and analysis. A further strength is the explicit attention to reflexivity and the recognition that "Nobody's perspective is neutral," which we interpret as a prompt for authors to consider reporting research team positionality alongside more typical academic strategies to account for bias in equity-relevant observational studies. We also recognize that such transparency is necessary but insufficient without parallel efforts to address structural inequities in how research agendas, funding, and authorship opportunities are distributed [44].

However, the study has limitations. Only 11 key informants were interviewed, which limits the range of perspectives and may not capture the diversity of views across the global research community. Participants were purposefully sampled from people already engaged in equity-relevant research and reporting; perspectives of researchers who do *not* prioritize equity, or who are skeptical of equity-focused reporting, are under-represented. Additionally, recruitment through networks linked to the STROBE-Equity project may have favoured individuals more supportive of reporting guidelines or more aligned with the project's aims. Importantly, people with more constrained time and resources (who may face the steepest practical barriers to equity-relevant reporting) could have been less likely to participate. These sampling features, together with the specific temporal context of data collection (post COVID-19, during active decolonizing and global-health equity debates) means that findings may not transfer across time, settings, or disciplines.

There are also important methodological limitations: using qualitative description and framework analysis prioritizes practical thematic insights over deep interpretive or theoretical development, which may limit how much we can speak to underlying epistemologies or power structures beyond what participants articulated. Further, the coding framework, developed within the STROBE-Equity team, is shaped by our team's prior commitments and positionalities despite multiple-coder and team review. Finally, the relationships between some participants and the broader STROBE-Equity initiative, as well as the interpersonal dynamics inherent to qualitative interviewing, may have influenced what participants felt comfortable sharing and how they framed their views. To protect confidentiality in a small, highly connected field, we reported participants' roles and regions in summary form – a strategy that was used in the development of the CONSORT-Equity extension [30] and that was carefully considered and agreed upon again with the STROBE-Equity team [14] – which may under-represent how lived experience and positionality shaped the perspectives in this paper. At the same time, these careful confidentiality safeguards were intended to support participants' in speaking candidly about equity-relevant reporting.

Future research

Given this study's focus on the perspectives of individuals with prior experience in equity-relevant observational studies, future research should aim to capture a wider range of perspectives, including those less familiar with reporting on equity.

The interviews revealed several areas that may be valuable to explore in future research. While the participants noted potential benefits for improved equity reporting, the specific impacts on research practice and outcomes remains speculative. Conducting a long-term impact assessment of the STROBE-Equity extension could provide valuable insights into its effectiveness in enhancing the representation and reporting of equity-deserving groups.

Participants also emphasized the need for upstream systemic adaptations to make reporting on equity more feasible in observational studies. Further research could investigate how journal editors and funding bodies can promote and integrate equity-relevant reporting guidelines without increasing researcher burden.

Additionally, exploring the development and effectiveness of training programs and support tools for implementing the STROBE-Equity extension could help bridge the "know-do" gap, potentially through global studies on practical decision-making, training formats, and content for researchers worldwide. Our findings highlight important unanswered questions about what counts as "equity-relevant" in practice. Participants suggested that equity

considerations can arise across any health topic and at every stage of the research lifecycle. This uncertainty underscores the need for further conceptual and empirical work to systematically recognize the implications of research decisions and use tools such as STROBE-Equity to assess the equity relevance of observational studies.

Conclusions

Findings show that participants see equity as a complex, dynamic issue and emphasize the need for clear and consistent definitions of equity-related terms and concepts, noting that varying interpretations across disciplines can hinder meaningful comparisons. They advocate for establishing a common language and providing practical guidance to help researchers determine when and how to incorporate equity-relevant considerations. Participants also described practical barriers to reporting on equity such as time, resource constraints, and publication limitations but suggested that consistent equity reporting would facilitate more robust evidence synthesis. Additionally, they stress the importance of transparent reporting, even when equity goals are not fully met, to promote accountability.

Overall, participants viewed the STROBE-Equity extension as a potentially valuable tool for raising awareness, structuring reporting, and encouraging reflection on biases. They anticipated that using the extension could support more equity-attentive study designs and reporting practices.

Abbreviations

CONSORT	Consolidated Standards of Reporting Trials
EDI	Equity, Diversity, Inclusion
GRIPP	Guidance for Reporting Involvement of Patients and the Public
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analyses
SRQR	Standards for Reporting Qualitative Research
STROBE	STrengthening the Reporting of OBservational studies in Epidemiology

Supplementary Information

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Supplementary Material 1: Additional file 1: Guidance for reporting Involvement of Patients and the Public (GRIPP) 2 short form reporting checklist.

Supplementary Material 2: Additional file 2: Standards for Reporting Qualitative Research (SRQR) reporting guideline.

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Author contributions

Conceptualization: VW, JJ, SF, LM, EG, OD. Methodology: JJ, DS, VW. Investigation (Data Collection): DS, KA, JJ. Formal Analysis: DS, JJ. Validation: VW, SF, LM, OD, EG. Project Administration: JJ, VW, EG. Funding Acquisition: VW, JJ, SF, LM. Resources: VW, JJ, Bruyère Health Research Institute. Writing – Original Draft: DS, JJ. Writing – Review & Editing: All authors contributed to reviewing and editing the manuscript for intellectual content and approved the final version. Supervision: JJ, VW. Corresponding authors: JJ.

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Data availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

This study received ethics approval from the Bruyère Health Research Institute Research Ethics Board (Protocol # M16-21-025).

Consent for publication

Not applicable.

Competing interests

LCG contributed as a doctoral student and during his study time. While he is employed by the Pan American Health Organization (PAHO/WHO), the ideas expressed in this manuscript are the authors' own and do not necessarily reflect the decisions and policies of PAHO/WHO. No other authors declare competing interests.

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